# Virginia START Third Quarter Progress Report for Implementation of VA START Services 7/12-3/13

# **Update: Challenges faced in START Service Development**

The implementation of a statewide service to provide support to individuals with complex and diverse needs presents many challenges. Planning for development and implementation of VA START occurred for sometime before the VASTART programs began providing services in earnest. The process has been complicated by barriers, but significant progress is being made and people have benefited from the efforts to date.

While the programs opened beginning in June, they were not equipped to provide a full array of Clinical team or Respite START services on the day they began to accept referrals and could play only a limited role. In hindsight, this may have undermined the process. To begin with the Clinical team and then implement therapeutic respite has been common practice for START teams. However, these always included the essential roles of Psychologist and Psychiatrist on the team prior to accepting referrals.

In Virginia, three of the Clinical Teams had long periods (Regions 1,4 and 5) without Clinical Director and Medical Director positions in place. Unfortunately, this limited the services they could provide. Region 1 only recently established solid leadership and continues to operate without a full time clinical psychologist. Region 5 filled their Clinical Psychologist and Psychiatrist positions in early March. Region 4 has had difficulty in attaining a qualified Psychiatrist and only recently has begun to work with one. The Team Leader position was also vacant in several regions. In addition, there has been turnover in the START Coordinator position in several of the Regions. However, it appears that in most locations, the teams are now in place.

START Respite is a central service and is relatively new to all regions. There were the typical and atypical obstacles to developing these services ranging from licensing and construction to securing a site and community opposition. There is also an ongoing need to train an entire team of professionals who are implementing a program that has never been operated in the state before, in the context of partnering with other providers in the community. All this is occurring while the system as a whole is changing. Despite these challenges, Regions 3 and 1 have provided effective respite services and are fully underway. Region 2 began respite services in March, and are expected to do well.

Another challenge has been to create an understanding of our mission. Given the dearth of qualified professionals in many locations of the state, a primary goal is to develop and train highly skilled professionals and future leaders in the field so that the safety net for the community system will be solidly in place, flexible to meet the needs of a diverse group of people, and cost effective. These has required a great deal of time in training START teams, and training will continue throughout the process. START Coordinators and Respite Directors are expected to meet standards established to be certified in the coming months. This is important to the sustainability of the program.

We are moving toward more proactive rather than reactive service delivery. This requires a better understanding of the individuals and their system of support, but has proven in to have long term positive effects on outcomes overall. While providing immediate support to intervene in crises, the team is also encouraged to take the time needed to provide comprehensive assessments of the clients referred. This is a balance that takes practice, to provide what the system needs immediately but to also engage in a dialogue and analysis to attain a more comprehensive understanding of what lead to the problems in the first place.

It is our experience that effective action and long term solutions comes from providing accurate assessments. Many of our individuals received services to control behavior rather than understand what a particular problem presentation can be telling us. Comprehensive assessment can be a painstaking process, especially when records are not readily available and true knowledge of the person's history and conditions has many gaps. There has been some resistance to this process, but given our mission to be proactive rather than reactive, it is our hope that stakeholders will continue to support this important effort.

Fortunately at this juncture, 3/5 of the state is now fully under way.

Following is a statewide overview, and does not report individual Regional progress. The local START teams are expected to provide region-specific summaries. The goal of this report is to describe trend analysis and progress with regard to the development and implementation of VA-START statewide.

# **Implementation of VA START Services Summary**

Following is an analysis of cumulative data reported in SIRS up until the end of this reporting period (3/31/13). It is important to note that we are still very early in the process. In some cases, data has not been reported or is under reported. However, given those limitations in the process, the data in this report does provide an informative portrayal of services and supports provided statewide so far.

# **Background**

Since Regions 1 and 2 were not licensed until December, and Regions 4 and 5 do not have out of home Respite programs, services reported are not all being provided statewide throughout the reporting period. The most significant provider of services is located in Region 3 where all services are being provided and reported.

To date, 350 individuals have been entered into the SIRS statewide, (an addition of 117 individuals since the last quarter's report); this is an increase of 33% in the number of individuals served. Based on the rate of referral and the limits on numbers of START services offered to date, the number of individuals referred to START is expected to triple in the next year since the locations with the largest population densities were not yet fully operational during the reporting period. It is reasonable to estimate that 700-1000 people will be supported through START services statewide once the system is fully operational.

#### **Client Data**

Following is data from referrals during the period that ended on December 31, 2012. There were a total of 233 client records were entered into the SIRS system between July 1 and December 31, 2012. This means that more than 120 individuals have not yet been entered into the system. The lack of documentation undermines the ability to get an accurate picture of individuals served. The recommendation section of this report will address this important issue.

#### **Non-emergency Referrals to START**

The data indicate that the vast majority of referrals came from case managers/care coordinators (90%). Emergency/crisis services referred 4%, family members referred 2%, and residential and day program providers each referred 1%.

### **Population information**

The following provides key information about the population served by VASTART.

#### Gender

As indicated in the table below, 56% of all referrals were male, while 44% of referrals reported were female. This is a slight increase in the male population when compared to the female population when compared to the last reporting period.

Gender	Number	%
Female	155	44.29%
Male	195	55.71%
Total	350	100.00%

#### Age

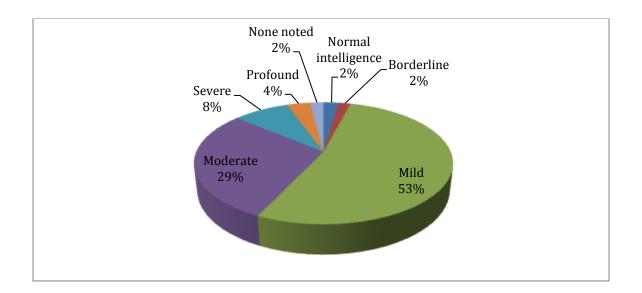
The age range of referrals was from 18-71. The mean or average age is 34; the median age was 30; and the mode or most common age reported was 22. The mode age dropped from 26 to 22 this reporting period. The transitional youth population is one that often is referred to START for assistance.

	Descriptive Statistics for individuals by	
Age	Age	
Oldest Age	71	
Youngest Age	18	
Mean Age	33.65	
Median Age	30	
Mode Age	22	

# **Level of Intellectual Disability**

According to the data reported to date, as expected, the predominant number of persons referred has mild intellectual disability (53%), followed by moderate ID (29%), severe ID (8%) and profound ID (4%). The population continues to be more disabled than the general population of service users and the newest referrals are more disabled than in the last reporting period with increases in the Severe, Profound, and Moderate groups and a drop in the mild group to 53% of the population. In addition, 6% of individuals referred do not have a diagnosed intellectual disability. Since you must half a developmental disability to meet the criteria to be admitted to START, it is likely that this group represents the DD population that is not eligible for ID services. This is an increase from the last reporting period.

Level of Intellectual Disability	Number of Individuals by level of ID reported	Percent of Individuals by level of ID reported
Normal intelligence	8	2.31%
Borderline	6	1.73%
Mild	184	53.03%
Moderate	101	29.11%
Severe	29	8.36%
Profound	12	3.46%
None noted	7	2.02%
Total	347	100.00%



# Mental Health Diagnoses at time of referral

The total number of individuals entered into the SIRS database was 350. Of those 222 (63%) had mental health diagnoses reported. However, the data does provide some insight into the current population of service users and is documented in the table below. It is noteworthy that 20% of the population has a diagnosis of autism. This number may increase as more individuals with autism who do not have ID enter the service system.

The distribution of diagnoses is not surprising and is consistent with other START populations in the U.S. where the primary issues are mood and anxiety disorders.

With regard to the number of reported MH diagnoses, the majority (52.70%) has one diagnosis while the remainder has two (29.28%) and three (15.32%). Six individuals have four diagnoses (2.7%). Again, a significant number (47%) has no diagnosis reported, we are not sure if this means they are not accessing MH services when they need them or underreported in SIRS or both since nearly 100% of the population is medicated with psychoactive medications.

Psychiatric Diagnoses	Number of individuals by current types of psych diagnoses reported	Percent of individuals by current types of psych diagnoses reported
Anxiety	41	18.47%
Autism	45	20.27%
Mood -	101	45.50%
Psychotic -	61	27.48%
Adjustment disorder Impulse control	10	4.50%
disorder	43	19.37%
Personality disorders (Axis II) Substance abuse	11	4.95%
disorder	4	1.80%
Total diagnoses	266	100 000/
reported Mean diagnoses	366	100.00%
reported	1.68	N/A
Mode diagnoses reported	1	N/A
1 diagnosis reported	117	52.70%
2 diagnoses reported	65	29.28%
3 diagnoses reported	34	15.32%

4 diagnoses reported	6	2.70%
No dx reported	128	36.57%

# Other disabilities reported at the time of referral

The table below indicates the number of disabilities reported in the SIRS for the population of START service users. A total of 28 individuals were reported with disabilities in addition to IDD and mental health diagnoses already reported. Of those individuals, 25%% reported to have hearing impairment and 42.86% had communication and speech problems. This was followed by ambulation and vision problems. It is hoped that more attention to these important vulnerabilities in the population will be attended to in future reporting and planning.

Other disabilities	Number of individuals by current disabilities reported	Percent of individuals by current disabilities reported
Hearing	7	25.00%
Physical/ ambulation	4	14.29%
Speech/Communication	12	42.86%
Vision	5	17.85%
Total individuals		
reported	28	

#### Medical Diagnoses at the time of referral

Medical issues are important to address in the population. Only 165 individuals or 47% of the service users have reported medical conditions in the SIRS database to date. Of those individuals, more than half have more than two chronic medical conditions. This is significant given the young age of the population with a median age of 22 and average age in the middle 30's. Nearly 42% of those being reported have a neurologic condition (seizure disorder), followed by several conditions often associated with psychiatric medication side effects including GI problems (26%), Type 2 diabetes (16%) and cardiovascular disorders (16%). The START team will be using the MEDs and other assessments to better monitor medication effects and educate providers. In addition, it is important to understand the effects of chronic medical conditions on the psychological well-being of service users. It is expected that this will be a focus of the services provided by START teams as we move ahead with this project.

# **Reported Medical Conditions**

W 11 10:	Number of individuals by current	Percent of individuals by current med
Medical Diagnoses	med diagnoses reported	diagnoses reported
Cardiovascular	26	15.76%
Dental/Oral	2	1.21%
Dermatology/Skin	9	5.45%
Ear/Nose/Throat	4	2.42%
Endocrine/Diabetes	27	16.36%
Eye disorders	7	4.24%
Gastro/Intestinal	43	26.06%
Genitourinary	8	4.85%
GYN	5	3.03%
Hematology/Oncology	6	3.64%
Hepatic/Biliary	4	2.42%
Immunology/Allergy	15	9.09%
Infectious disease	3	1.82%
Neurologic	69	41.82%
Nutritional disorders	9	5.45%
Pulmonary disorders	19	11.52%
Total diagnoses		
reported	293	100.00%
Total individuals with		
reported medical		
diagnoses	165	55.74%
Mean diagnoses		
reported	1.79	N/A
Mode diagnoses	1	NI /A
reported	1	N/A
1 diagnosis reported	88	53.33%
2 diagnoses reported	44	26.67%
3 diagnoses reported	18	10.91%
4 diagnoses reported	10	6.06%
5 or more diagnoses	_	0.000/
reported	5	3.03%
No medical dx	105	<b>F2.0</b> (0/
reported	185	52.86%

# **Residential information**

# **Residential Setting at Time of Referral**

Following is the reported information with regard to residential placement. An important factor that contributes to or undermines stability for service users is a stable home life. As noted in the data, a primary issue for families is that they communicate concerns about the ability to support their family members, especially during times of difficulty (see emergency contact section).

However, it is important to note that in addition, residential placement and the lack of permanence is another factor that needs to be explored when looking at the data. 37.14% of the population overall reported to have had multiple residential placements in the last five years. This percentage would be greater if we consider the fact that 35% of the population has never had a residential placement and remained at home.

Multiple residential placements over the last 5 years (at point of referral)	Number of individuals with multiple placements	Percent of individuals with multiple placements
No	220	62.86%
Yes	130	37.14%
Total	350	100.00%

The table below presents a frequency distribution of residence at the time of referral. This finding indicates that with regard to community housing, the VA START program continues to be on target in supporting families (35.15%) or people who reside with few paid supports (an additional 6%).

There is a need to receive more referrals from locations so that START programs can be better able to assist in transitions to community. To date less than 10% of the population is referred from state operated centers, hospitals and other facilities. This is expected to increase over time.

Living situation at time of referral to START	Number of Individuals by type of living situation reported	Percent of Individuals by type of living situation reported
Assisted Family Living		
(AFL)	15	4.55%
Community ICF/MR	1	0.30%
Family home	116	35.15%
Foster care home	8	2.42%
Group home	140	42.42%
Homeless	3	0.91%
Independent living	9	2.73%
Jail	0	0.00%
Psychiatric hospital	9	2.73%
State operated I/DD center	8	2.42%
Supervised apartment	4	1.21%
Supported living	6	1.82%
Other	11	3.33%
Total	330	100.00%

The average number of problems reported per referral was approximately 3. The majority of presenting problems at the time of referral were as expected due to some form of aggression (52%), followed by general mental health symptoms (14%). Other mental health symptoms reported included suicidal ideation (4%), self-injurious behavior (4%) and decreased ability to function (6%).

Presenting problems also included some service related problems. A number of individuals were identified as at-risk of losing placement (8%); need for family assistance (6%) the need for diagnostic and treatment assistance (3%), and transition from hospital (2%).

# **Psychiatric Hospitalizations**

As would be expected, a significnat numer of START service recipients have been admitted to psychiatric hospitals in the past year (35%) with multiple admissions (an average of 2 admissions per client). When reviewing the prior five years, the number of people hospitalized increased by 7% and the recidivism rate during this period doubled. This is a target goal of the START Program which is to help avoid unnecessary hospitalizations and reduce recidivism rates.

Psychiatric hospitalizations in the last year (at point of referral)	Number of individuals reporting multiple hospitalizations in the last year	Percent of individuals reporting multiple hospitalizations in the last year
No	228	65.14%
Yes	122	34.86%
Total	350	100.00%
Range	1-15	
Mean	2.2	

Psych hospitalizations in the last 1-5 years (at point of referral)	Number of individuals reporting multiple hospitalizations in the last 1 - 5 years	Percent of individuals reporting multiple hospitalizations in the last 1 - 5 years
No	204	58.29%
Yes	146	41.71%
Total	350	100.00%
Range	1-30	
Mean	3.66	

Number of Prior Psych Hospitalizations	Total number of hospitalizations	Percent of prior psychiatric hospitalizations
In past 1 to 5 years	535	66.46%
In past year	270	33.54%
Total	805	100.00%

# **Emergency services provided by VA START**

# Number of people served in emergency services

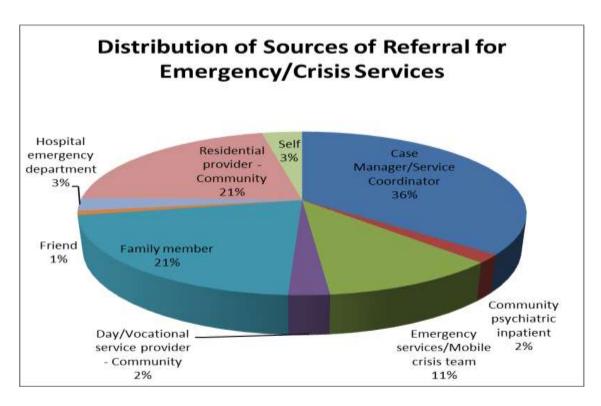
Below are the data reported in the SIRS with regard to referrals for crisis and/or emergency services. A total of 79 service users or 23% of the START population to date were referred for a total of 121 emergency or crisis events. 42 individuals or 53% of the population of 79 emergency service users had more than one crisis contact. The average number of crisis contacts was 1.53 per service user.

Individuals that were referred for and received emergency/crisis	79
services	
Total number of Emergency/Crisis services referrals	121

#### **Crisis referral Sources**

Following is the distribution of referrals sources at the time of crisis contact for the reporting period up to March 31, 2013. Not surprisingly, case managers and service coordinators continue to be the primary sources of emergency referrals. However, the numbers are already shifting even at this early stage of program development. It is noteworthy that families are using the START program at the same rate as residential providers at 21% of the emergency referral sources each, followed by emergency services/mobile crisis at 11%.

Source of Contacts/Referrals for Services	Number of Sources	Percent of Sources
Case Manager/Service Coordinator	42	35.59%
Community psychiatric inpatient	2	1.69%
Emergency services/Mobile crisis team	13	11.02%
Day/Vocational service provider - Community	3	2.54%
Family member	25	21.19%
Friend	1	0.85%
Hospital emergency department	3	2.54%
Law enforcement	0	0.00%
Legal advocate	0	0.00%
Residential provider - Community	25	21.19%
School	0	0.00%
Self	4	3.39%
State operated I/DD center	0	0.00%
State psychiatric hospital	0	0.00%
Other	0	0.00%
Total	118	100.00%



# **Problems Reported at the time of Crisis Contact**

The table below indicates the percentage of the population that presents a given problem along with the distribution of problems reported at the time if crises. 100% of the population reported to be suffering from acute mental health symptoms at the time of emergency referral along with 90% of the population exhibited some form of aggression as a problem reported at the time of crisis. It is also very noteworthy that 52% of people referred were considered at risk of losing placement at the time of the emergency referral. Also of note is that 27% of the referrals were of families in need of assistance.

Problems reported at time of contact	Number of people	% With that problem
Aggression - all	71	90%
At risk of losing placement	41	52%
Decrease in ability to participate in daily functions	45	57%
Diagnosis and treatment plan assistance	19	24%
Family needs assistance	22	28%
Mental health symptoms	79	100%
Self-injurious	19	24%
Transition from hospital	12	15%
Total reasons		
Total individuals with reported reason for		
emergency/crisis contact	79	

Below is the type of emergency assessment provided by the START team and location of the assessment reported into the SIRS. 60% of emergency assessments were conducted in people's home in person. This is a very good finding and consistent with the goal of mobile outreach support during times of crises. It is important to note that only 6% of the assistance was phone contact only. The teams are being encouraged to provide face-to-face assessments in the juncture of implementation in order to develop relationships with community partners, families and service users. At some point the use of telephonic assessments will increase for known individuals and systems.

Type of emergency/crisis assessment	Number of Types of emergency/crisis assessments	Percent of Types of emergency/crisis assessments
In-person: Doctor's office	3	2.48%
In-person: Emergency		
room	19	15.70%
In-person: Individual		
residence	73	60.33%
In-person: START office	2	1.65%
In-person: MH outpatient		
clinic	0	0.00%
Phone consultation only	7	5.79%
Other	17	14.05%
Total	121	100.00%

It is essential that the START teams provide timely assessment and intervention services. It is important to note that this particular data was not consistently reported in the SIRS. For 26 people or 33% of the crisis responses did not include response times in the SIRS. This is a problem that undermines the ability of the analysis. The table below outlines the reported response time for 53 people out of the 79 (67%) of individuals who received emergency or crisis services. Of the 79 individuals, 26% of the coordinators responded in less than two hours, 18% reported a response time of 2 hours or more of which two individuals had a 3 hour response time. The program is still in development, but it is noteworthy that we are not on goal for a maximum two-hour response time at this point in service delivery. This issue will need to be addressed.

#### Reported Response time following emergency request

Response time	Number of events by response time	Percent of events by response time
Less than 2 hours	31	25.62%
2 hours or more	22	18.18%
Unknown	26	32.91%
Average response time		
reported	1 hour(s), 45 minute(s)	

total of 53 individuals

#### Outcomes/ primary dispositions during crisis contact

The following table provides an overview of the outcomes associated with crisis contacts reported in the SIRS (21 reported crisis contacts had no documented outcomes for this analysis). There is one primary outcome noted for each crisis contact. There were a total of 121 crisis contacts for 79 individuals reported. For the contacts reported, the majority of outcomes (58.65%) were in home respite support provided by their regional START team. This was followed by returning home without additional supports (18.27%) and admission to START respite (11.54%). There were six episodes that resulted in admission to state psychiatric facilities reported statewide or 6% of the outcomes.

Final outcome/disposition of referral to emergency/crisis services	Number of Outcomes	Percent of Total Outcomes
In-home respite support	61	58.65%
Maintain current setting	19	18.27%
Referral out for services	2	1.92%
START emergency respite admission	12	11.54%
State psychiatric hospital admission	6	5.77%
Total crisis contacts and outcomes	100	
21 not reported		

#### **Arrests**

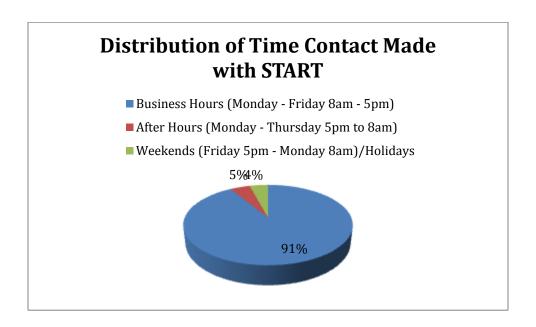
Several individuals have been reported by the regions to be in jail, with a total of 8 individuals noted to have been in jail in the last 12-month period as of the time of referral to VA START. In at least two cases, one in Region 4 and one in Region 5, there was expressed concern on the part of the START Clinical Directors that the individuals placed in jail were not getting the proper medical attention. Namely, there medications as prescribed were abruptly discontinued at the time of arrest. In one case, the Clinician reported that the individual has a seizure disorder and may have had several seizures while in jail as a result of the sudden discontinuation of his medications. A straw poll conducted of all START team in March indicated that all teams have concerns about clients being arrested and placed in jail.

#### Additional START Clinical team Services

START Clinical Team time is tracked in the SIRS database to gain a better understanding of services provided and related outcomes. This section of the report will review information gathered to date. Again it should be noted that this is a very new program so that the data reported only reflect a snapshot of a brief period of time and cannot be considered a trend in terms of long-term service outcomes.

# When services are provided

The vast majority of VA START services statewide have been provided during business hours (91%) with 9% of service provided after hours and on weekends. This can be explained by the roll out of the programs where the majority of services were only offered during business hours and only offered after hours and on weekends in later months in this first year of operation statewide.



### **START Specific Assessments and Training Provided**

The table below provides the number of START clinical team Cross systems crisis prevention and intervention plans (CSP); Comprehensive Service Evaluations (CSE) and Clinical Education Team reviews (CET) provided by each region. All are core elements of service delivery for each program. It is expected that the vast majority of the individuals supported will have CSPs, while only about 20% will have CSEs.

CET meetings are forums required to occur monthly. The reporting indicated that the implementation of these important services has been sporadic with regard to statewide trends so far. Some of this can be explained by the differing stages of development. These services are being taught to the teams so that productivity is expected to lag somewhat. In addition Regions 3 and 5 were not expected to begin their CETs until later in the fiscal year, so that it is expected that they will be provided by the next reporting period. Region 2 did not have a license for much of the reporting period but was able to provide CETs. This may help to explain their numbers. Each region must have a minimum number of CSEs, CETS and CSPs completed in order for their coordinators to be proficient enough at each to be certified. The numbers may indicate that certification will take longer to achieve than was expected in some regions and that Region 5 may be ready for certification sooner than some others.

The development of cross systems crisis prevention and intervention plans takes about 30 days to complete when the team has agreed to work together in a joint effort to develop a clear strategy. Since this process is new in Virginia, it has taken a bit longer to accomplish and provisional plans are used as a way to engage the system in working together while the team learns to collaborate more effectively. Each time this is accomplished, the members of the team become more willing and able to collaborate in the development of effective plans. This is an important process intended to improve the competence of the system as a whole. Dr. Weigle has been working with teams to review their CSPs, and we have had several trainings and workshops. The teams are improving in

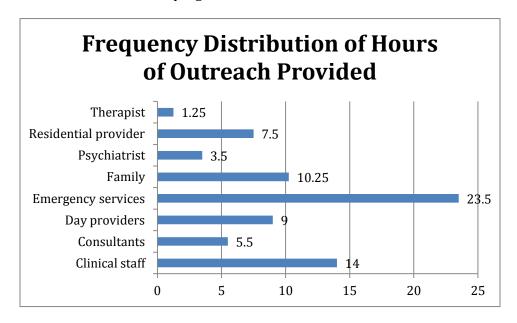
their skills and it is expected that the CSP process will improve over time and the time it takes to develop the plans will be more in line with the 30 days it takes in other states.

Number of CSPs, CSEs, CET forums completed by region as reported in SIRS

Region	# CSP	#CSEs	# CET forums
1	1	0	2
2	8	0	8
3	27	7	0
4	20	0	1
5	86	13	0
Totals	142	20	11

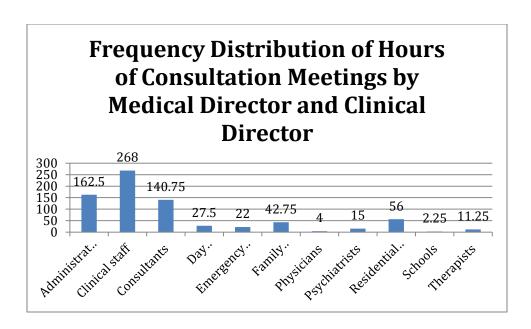
#### **Outreach Services**

The graph below presents the frequency distribution of hours providing outreach services per coordinator statewide as was reported in the SIRS by START Clinical Teams. The data indicates that time required to work with emergency service is far greater than any other time when providing outreach or linkage supports. This can be explained by the complexities often involved with collaborating with emergency service teams during times of crisis. Again, this is being reported early in the implementation of the program so that further analysis of outreach outcomes will be more informative as the program moves forward.



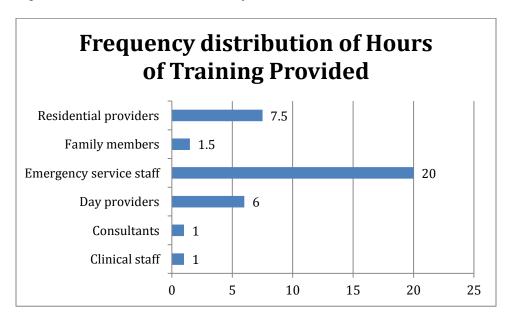
# **Consultation meeting provided by Clinical and Medical Directors**

Below is the distribution of services provided by Medical and Clinical Directors as reported in the SIRS. Again this is very preliminary data.



#### Training provided with Regard to START services and supports

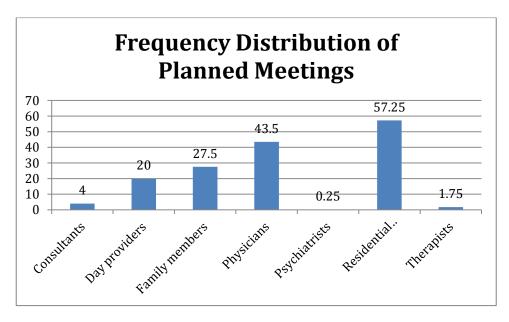
Below is the reported time spent training members of the community system about START services as reported in the SIRS. The majority of trainings have been provided to Emergency services to date. More training is needed including the provision of CETs and topical trainings and will be reported in future summaries as they occur.



#### On going planning meetings for teams of START clients

The table below portrays very preliminary data entered into the SIRS with regard to time spent during planning meetings statewide. The majority of time recorded in this very early period reflects meetings with residential providers (57.25 hours recorded in the data), followed by time spent meeting with the individuals' physicians (43.5hours), family members (27.5 hours) and day program providers (20 hours). Again the small amount of data indicates that this is a new program

but also that there may be some reporting errors. It is expected that this will be a more meaningful assessment of time spent with partners as the programs progress and reporting improves.



#### **VA START Respite Services**

The following sections will provide a review of respite service outcomes reported into the SIRS up until March 31<sup>st</sup>, 2013. It is important to note that all services are new, especially respite. This report includes data for three therapeutic respite facilities. Region 3 opened in December 2012, Region 1 opened in January 2013, and Region 2 opened in March 2013. Early data cannot reflect trends in the system but can provide a limited look at progress so far. All regions while opening in months indicated provided only planned respite in the first 30 days of operation. In spite of this the data shows that more emergency than planned service were provided overall. Region 3 provided the vast majority of services and supports through their respite programs to date. While Regions 4 and 5 were able to provide in home respite prior to operating their respite sites, Regions 1, 2 and 3 began providing both in home and emergency services at approximately the same time.

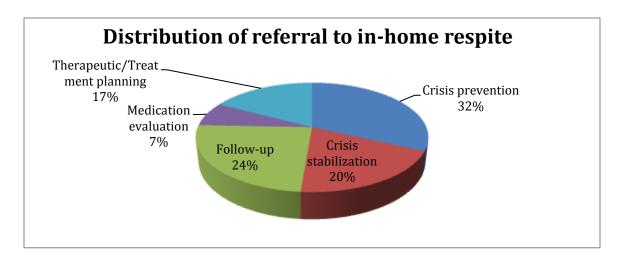
# **In Home Therapeutic Respite**

All five regions now provide in home therapeutic respite. As a result the greatest number of individuals has been served in this respite category. Region 3 provided the greatest number of services to date, followed by regions 1 and 5. Regions 5 and 4 have only begun to provide in home respite services at the end of the reporting period that began in July and ended in March of 2013.

The tables below describe services provided through in home therapeutic respite. This is also referred to crisis stabilization in home supports in the DOJ settlement agreement.

A total of 50 individuals received in home respite as was reported in the SIRS Between December 1, 2012 and March 31, 2013. All regions with the exception of Region 4 provided these services throughout the last quarter of the reporting period. Region 4 began to provide some in home respite services during this period.

The graph below shows the reasons for referral for in-home respite with the majority focused on crisis prevention and stabilization (52%). This is followed by therapeutic treatment planning support and medication evaluation with the consultation of the START Medical Director.



Although many in home respite services are provided to help stabilize and emergent situation, they are also provided to assist in assessment, follow-up after discharge from the respite home and preventative support for people in need. The table below provides a frequency distribution of services provided in categories based on the therapeutic goals of in home respite.

Services needed during In-Home	Number of	Percent of
Respite	individuals	individuals who
		received this service
Crisis prevention	47	94%
Crisis stabilization	43	86%
Follow up	44	44%
Medication evaluation	13	26%
Therapeutic/Treatment planning	35	70%
Number of individuals served	50	

#### Therapeutic respite program site services

Virginia START emergency respite services have been launched in three of the five regions of the state, with Region 3 providing the most services having opened prior to regions 1 and 2. Regions 4 and 5 do not have a date established to open their respite programs as of yet. As of this report writing, region 5 is seeking a temporary site while renovating an identified permanent site. Region 4 is also seeking a temporary site and has had difficulty with community opposition for their current permanent site. Both programs are unlikely to open this fiscal year unless remedies to this

issue can be addressed soon. This undermines their ability to provide the full compilation of START services in their regions.

Region 3 has been operating the longest and is the most well developed program in the state. Region 1 has been open for several months. However, the program lacks a permanent Director and Clinical Director as of this reporting period. This undermines the ability of the program to develop as needed. In spite of this, the Region 1 program has already made a difference and has had several very positive admissions. In addition, a program director has been identified and will be starting in April, 2013.

There has been a great deal of discussion about the role of the START team's therapeutic respite program in "replacing" the state operated training centers. While the need for these facilities may be reduced due to improvements in the community system, this is not an expressed or explicit goal of the program. The goal of this program is to work collaboratively with other community providers so that individuals receive the appropriate family support, person centered mental health, primary medical, residential, vocational and recreational resources to live successfully in the community. As part of the "safety net" that includes these partners along with the emergency service teams in local communities, the VA START respite and clinical team provide therapeutic supports to assist individuals and their system of support in improving outcomes. It is important to address this central issue with each region and it members. An important measure of success of this program will be the engagement and enhancement of the community system as a whole. Members of the START teams report that there has been resistance to support the success of the START programs to prove the need for training centers. This is a problem that can undermine the success and mission of the program.

Below is data in the SIRS reported between July 1, 2012 and March 31, 2013, the first three quarters of the fiscal year.

#### **Emergency therapeutic respite**

VA START Emergency or Crisis respite has been provided to a total number of 15 individuals in this reporting period.

The average length of stay in emergency respite was 18.25 days. The stays ranged from 7 to 30 days. In addition, the recidivism rate is very low. Only 13% returned for an emergency admission after discharge and no one had more than two admissions to date. Some of the individuals also received in home follow up support and or planned admissions to the program following emergency admissions. These findings are consistent with the program expectations. However, it is important to note that the numbers are very small so that we will keep close attention to trends as increase in service use occurs over time.

Number of individuals referred for Emergency Respite	15
Average Length of Stay	18.27 days
Recidivism	13%
Maximum	2 admissions

The frequency distribution below portrays the reasons expressed for emergency respite admissions in the 15 individuals who received emergency respite statewide. The top reason was that the

individual exhibited aggressive behavior at the time of referral (93% of population), followed by decrease in ability to function (87%), risk of losing placement (80%), mental health symptoms (73%) need assistance in diagnosis and treatment planning (60%), and family assistance needed (40%). Several individuals also had self-injurious behaviors (47%), suicidal ideation (not committable, 20%) and transition from hospital inpatient unit (20%). As was mentioned earlier, these will be analyzed quarterly to assess shifts in trends and the number of services and service users increase over time. However, the information provided reflects that programs to date are meeting their mission in providing emergency therapeutic respite for the reasons outlined below.

#### **Planned Therapeutic Respite**

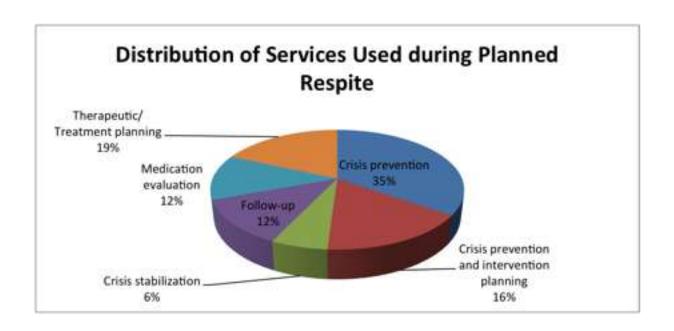
Planned therapeutic respite services are designed to support families and those who provide unpaid natural supports to individuals who are eligible for START services. This important service requires outreach and support in order to assist families in accessing therapeutic respite. It helps prevent crisis service use and helps families to remain together. It is a service that takes time for people to be aware of and feel confident in the provider to assist a loved one. To date 17 START service recipients have used planned therapeutic respite according to the data reported in the SIRS. Most of these services were provided in Region 3, with few provided in Region 1 and even fewer in Region 2 during this reporting period. The length of stay ranged from 2 to 5 days with an average of 3 days. This is right on target.

Number receiving Planned Respite	17
Total number of Planned Respite admissions	24
Range of stay	2 - 5
Average number of days	3

The table below outlines the START assessments and services provided while at planned respite. As noted, all recipients had a targeted goal of crisis prevention support, while 47% had assistance in cross systems planning, and 17% had a goal of crisis stabilization. Medication evaluation, follow up supports and therapeutic service design were also reported to be key components of the planned stays.

Services provided while utilizing START planned respite services	Number of individuals	Percent of individuals who received this service
Crisis prevention	17	100%
Crisis prevention and intervention planning	8	47%
Crisis stabilization	3	17.64%
Follow up	6	35.29%
Medication evaluation	6	35.29%
Therapeutic/Treatment planning	9	52.9%

The diagram below provides an outline of services provided to the individuals while receiving planned therapeutic respite, primarily at the Region 3 respite program.



# Trainings provided through the 2012-2013 Annual Online Training Series on Mental Health & IDD and number of participants

An important service provided by the VA START team is training through the national center to improve expertise in the system as a whole. The VA START programs have worked to overcome barriers with regard to technology and other issues to offer these important trainings. The trainings and number of training sites statewide are listed below. This is by number of sites participating and can include a number of participants in each site. It is noteworthy that the number of participating sites has increased in recent trainings.

- July 27, 2012 Physicians & Clinicians Series: Introduction to ID & Developmental Disorders VA START registered: 49
   Presenter: Jarrett Barnhill, MD, University of North Carolina Chapel Hill, Department of Psychiatry, Neurosciences Hospital
- August 24, 2012 Physicians & Clinicians Series: Mood & Anxiety Disorders in Persons with I/DD VA START registered: 43
   Presenter: Jarrett Barnhill, MD, University of North Carolina Chapel Hill, Department of Psychiatry, Neurosciences Hospital
- September 21, 2012 Physicians & Clinicians Series: Psychoses, Delirium & Other Neuropsychiatric Disorders VA START registered: 41
   Presenter: Jarrett Barnhill, MD, University of North Carolina Chapel Hill, Department of Psychiatry, Neurosciences Hospital
- October 26, 2012 Physicians & Clinicians Series: Autism & the Neuropsychiatry of Epilepsy, Sleep Disorders & Movement Disorders VA START registered: 38
   Presenter: Jarrett Barnhill, MD, University of North Carolina Chapel Hill, Department of Psychiatry, Neurosciences Hospital

- January 11, 2013 Multi-Modal Assessment/Treatment of Aggression VA START registered: 62 Presenter: Dr. William Gardner, Professor Emeritus, University of Wisconsin-Madison
- March 8, 2013 Attention-Deficit/Hyperactivity Disorder (ADHD) in ID VA START staff: 71 Presenter: Anne Desnoyers Hurley, Ph.D. Research Associate Professor, Institute on Disability University of New Hampshire & Tufts University School of Medicine

# **Affiliation and Linkage Agreements**

Affiliation and linkage agreements are key to successful implementation of START services. There are expressed concerns about service and resource provision, access to appropriate inpatient care, and the ability to consistently collaborate with mental health emergency service teams, residential and day program providers. It is essential that affiliation and linkage agreements be developed to clearly define roles and responsibilities in these and other important contexts as we move ahead.

Following is the information reported by Regions with regard to linkage agreements to date:

# **Region I Linkage & Affiliation Agreements:**

- · Horizon Behavioral Health (CSB)
- Rappahannock Community Services Board (CSB)
- · Harrisonburg-Rockingham Community Services Board (CSB)
- · Region Ten Community Services Board (CSB)

#### **Region II Linkage & Affiliation Agreements:**

Linkage agreement between Fairfax County Emergency Services and START

- · Prince William County ES and START
- · Alexandria County ES and START
- Louden County ES and START
- Arlington County ES and START

#### **Region III Linkage & Affiliation Agreement with:**

- · Alleghany Highlands Community Services Board
- · Blue Ridge Behavioral Healthcare
- · Cumberland Mountain Community Services
- · Danville-Pittsylvania Community Services Board
- Dickenson County Behavioral Health Services
- · Highlands Community Services
- Mt. Rogers Community Services Board
- New River Valley Community Services
- · Piedmont Community Services Board
- · Planning District 1 Behavioral Health Services

# **Region IV Linkage & Affiliation Agreements:**

- · Richmond Behavioral Health Authority
- Henrico Area CSB
- Goochland Powhatan CSB
- District 19 CSB
- Chesterfield CSB

- · Hanover CSB (request submitted)
- Southside CSB (request submitted)
- Crossroads CSB (request submitted)

#### **Region V Linkage & Affiliation Agreements:**

No linkage agreements have been officially signed. They are continuing to work on them with the ES departments. Region V is also working on a regional agreement that will define how START, case management, the training center, the state hospital, and ES will work together. These should all be completed during the quarter and completed by the end of the fiscal year on June 30.

# **Outstanding issues from last report**

Following are continued Systems issues to be addressed:

- 1. Identification of who is in the state hospitals in need of help from START. What is the process? There should be written policies and procedures shared with the START teams.
- 2. Engagement of START in developing transition and crisis plans for those leaving the training centers. There should be written policies and procedures shared with the START teams.
- 3. Expediting the assignment of case management to those who are eligible for ID or DD services when they are referred to START in an emergency situation. Is there a policy about this? Again, a written policy and procedures should be shared with the teams.
- 4. Bridge payments for residential providers for up to 30 days should be considered so that they can hold a bed open, and work actively with START team, respite and/or inpatient unit along with START to successfully return and remain at home. Providers are discharging clients not because they want to but because they cannot get funding to provide support unless the person is at their residence. This has been mentioned several times in discussions. START partners will not be effective unless they are able to work with START to learn how to more effectively serve clients in the community. The payment issue is an obstacle for some residential providers and needs to be addressed.
- **5.** There continues to be the need for written policies with regard to the ES teams and their partnership with START teams. While some progress has been made, ES teams need to be trained to better assess the mental health needs of persons with IDD. Training is available, and we await a plan to make this easily available to ES workers.
- **6.** It has become very apparent that the need for better medical screening is needed prior to admission to START respite programs. A request for all medical personnel

to work together with Bob Villa to provide guidelines was sent. Please respond to this important request.

#### **Conclusions and recommendations**

In reviewing the data it has become evident that there are issues to be addressed with regard to the lack of consistent documentation that will be addressed in the recommendations that follow. Despite this issue, the analysis provides the available data to accuarately portray the maturation of the system so far.

Although not included in this report, we encourage the regional advisory councils to hear some of the stories of individuals and families being supported and of the great personal efforts on the part of the teams as they review progress to date. Thank you to all of the stakeholders reviewing this document. Despite the challenges, we are encouraged by the progress so far, and look forward to your feedback.

Virginia is now in various stages of implementation for VA START. While Regions 1, 2 and 3 have been fully launched, Regions 4 and 5 are not expected to have site based respite services this fiscal year.

It is important to note that no respite program has been in operation for more than four months as of March 31, 2013. Until the system understands the resources available, there will be a lag in service requests. However, experience shows us that this increases over time. In North Carolina for example, the overall occupancy rate for respite is more than 80%.

Systems change takes organization, support from senior officials, communication and collaboration between all parties and stakeholders. This requires policies and procedures, affiliation and linkage agreements, data collection and reporting, protocols to problem solve, and clear understanding of roles and repsonsibilties to address the needs of our clients and their families. Many new systems and processes are being implemented and more training and support is needed as the implementation plan moves ahead.

Following is the support plan from the team at UNH to assist with the implementation and reporting processes:

- 1. Clinical Directors study groups monthly to prepare clinicians to provide CET trainings will continue.
- 2. SIRS data review will occur on a scheduled basis between Linda Bimbo and the START Directors to insure that data is entered in a timely fashion. We will be reviewing the database monthly and provide feedback ot Bob Villa and the Regional Directors to improve reporting accuracy. In addition, we will request they provide tighter supervision of the data entry and record keeping processes.
- 3. The development of a concrete START service planning format. There is an example that can be used from NH START. This will allow START Coordinators to document their action plan to support an individual and a system following the intake.

- 4. A member of the UNH START Center will meet with all Directors to review the MEDs and the ABC in order to determine if there are any obstacles in providing these assessments. There were not enough provided to report.
- 5. We will provide analysis of the Recent Stressors Questionairre with data submitted by Directors in the next quarterly report
- 6. UNH has taped an on line training for Emergency Service teams to learn about how to conduct an emergency assessment and work with the VA START teams. This is available to all Regions through their START Directors . We can provide a list of participants if requested.
- 7. The first satisfaction surveys will be conducted at the end of the fical year. We have attached the survey being used in other states. We will report the results of these surveys in the first quarerly report of fiscal year 2014.

#### Recommendations

- 1. It is of some concern that residential and day program providers may need additional support and training as we move forward to improve service effectiveness in the community. It is recommended that a task force be devleoped and include START programs to identify the needs of these very important partners and the role that VASTART can play in addition to emergency support and respite.
- 2. It has been reported that some individuals with DD who referred to VASTART do not have access to needed DD waiver services. This is also sometimes the case for individuals with ID. Clarification of access and eligibility for high risk individuals is needed.
- 3. It is recommended that every respite program have a family advisory group that meets regularly to provide feedback about respite services and other START supports. This will help families to have a voice and play a key role in the success of the program.
- 4. It is recommended that a risk committee be established in each Region with representative stakeholders who have authority to make rapid decisions and that the START team Directors participate in these committes, along with representative of Emergency services and mental health provider groups who serve the population. There needs to be a forum where stuck cases and complex issues can be addressed through a collaborative process in a timely and local fashion.

The final recommendation is that all stakeholders continue to support the VASTART teams to provide a new service in the state in the context of a system in transition with many challenges ahead. The state has provided resources and assembled a talented group of professionals and a dedicated group of providers to support them. It is key that everyone own the success of this effort.

Attachment 1 is an outline of VA START time tracking reported.

Attachement 2 provides the satisfaction survey to be implemented in June. Much progress has been made in the first 120 days of VASTART services implementation. Congratulations on this acheivement.

Submitted by, Joan B. Beasley, Ph.D , Director Karen Weigle, Ph.D., Director of Training Linda Bimbo, Director of Operations UNH/IOD Center for START Services

# ATTACHMENT I VA Service Outcomes (Time Tracking) Data 7/1/12-3/31/13

# START Service Outcomes Tracking (Non-individual/User related)

Data Element	# Of activities	Average per
	or entries	activity
Clinical Education Team (CET)		
<ul> <li>Meeting logistics</li> </ul>	3	2:00
<ul> <li>Reviewing CET case</li> </ul>	5	3:24
General Administrative Work (Gen)		
Billing Documentation	193	1:57
START related meetings	550	2:10
<ul> <li>Meetings with the Center for START Services national Team</li> </ul>	44	2:35
<ul> <li>Non-START related meetings/trainings</li> </ul>	129	2:45
<ul> <li>Phone calls related to operation of START</li> </ul>	521	0:55
<ul> <li>Phone calls NOT related to operation of START</li> </ul>	38	0:40
Travel time general	459	2:01
<ul> <li>Other administrative activities</li> </ul>	653	2:55
Supervision	184	1:54
Outreach, Training, and Systems Linkages		
Community-based training	12	1:21
<ul> <li>Outreach to clinical staff</li> </ul>	9	1:34
Outreach to consultant	5	1:05
<ul> <li>Outreach to day provider</li> </ul>	3	3:00
Outreach to emergency services	17	1:23
Outreach to family	7	1:28
Outreach to physician	0	0
Outreach to psychiatrist	6	0:36
Outreach to residential provider	8	0:55
Outreach to school	0	0
Outreach to therapist	2	0:37
Provided training to administrative staff	0	0
Provided training to clinical staff	1	1:00
Provided training to consultant	1	1:00
Provided training to day provider	3	2:00
Provided training to emergency services	10	2:00
Provided training to family	3	0:32
Provided training to physician	0	0
Provided training to psychiatrist	0	0
Provided training to residential provider	7	1:04
Provided training to school	0	0

Provided training to therapist	0	0
Time spent on affiliation and linkage agreements	19	1:49
Time spent as a participant in a training activity offered by the Center for START Services	158	3:23
On-call coverage/back-up	85	15:06

# START Service Outcomes Tracking (Time related to a specific individual)

Data Element	# Of	Average time
	activities or	per activity
	entries	
Clinical Education Team (CET)		
<ul> <li>Follow-up/communication with teams etc.</li> </ul>	13	1:20
<ul> <li>Reviewing CET case</li> </ul>	8	1:54
<ul> <li>Travel time related to CET</li> </ul>	21	1:09
Clinical Tools (CT)		
<ul> <li>A non-emergency review of a plan or evaluation</li> </ul>	46	1:19
<ul> <li>An emergency (un-planned) review of a plan or evaluation</li> </ul>	49	1:04
<ul> <li>Conference with START team by medical and/or clinical directors</li> </ul>	16	1:01
Conference with other START coordinators	22	0:41
<ul> <li>Time spent completing tools/forms</li> </ul>	137	1:56
<ul> <li>Time spent setting up conference calls or meetings for review/use of clinical tools</li> </ul>	37	0:34
Comprehensive Service Evaluations (CSE)		
<ul> <li>Gather and review information, records, etc.</li> </ul>	42	3:07
<ul> <li>Write Comprehensive Service Evaluation (CSE) report</li> </ul>	119	3:13
Review report with team	8	1:24
Develop action plan	12	1:25
<b>Cross-Systems Crisis Prevention and Intervention Planning</b>		
Collect and review relevant info	166	1:34
Complete brainstorm form with team	82	1:04
<ul> <li>Develop/write draft cross-system crisis prevention and intervention plan and distribute</li> </ul>	142	3:04
Review and revise cross-systems crisis prevention and intervention plan	86	1:57
Gather signatures	53	1:26
<ul> <li>Training staff, families, etc. to implement cross- systems crisis prevention and intervention plan</li> </ul>	13	1:25
Crisis Contacts		
<ul> <li>Meeting with client/family</li> </ul>	194	1:31

•	Meeting with client/family at psychiatric hospital	57	1:32
•	Meeting with general hospital	17	1:50
•	Facilitating admission to Crisis Stabilization Unit	3	3:00
	(CSU)		
•	Facilitating admission to psychiatric hospital	15	4:16
General A	Administrative Work (Gen)		
•	Chart review	520	1:15
•	Consulting with administrative staff (group)	131	1:15
•	Consulting with clinical staff (group)	242	1:06
•	Consulting with consultant	66	2:08
•	Consulting with day providers	32	0:52
•	Consulting with emergency services	16	1:26
•	Consulting with family	56	0:46
•	Consulting with physician	4	1:00
•	Consulting with psychiatrist	18	0:51
•	Consulting with residential provider	70	0:48
•	Consulting with school	2	1:07
•	Consulting with therapist	28	0:24
•	Meeting with consultant	113	1:50
•	Meeting with day providers	86	1:28
•	Meeting with emergency services	33	1:40
•	Meeting with family	151	1:25
•	Meeting with physician	7	1:22
•	Meeting with psychiatrist	28	1:07
•	Meeting with residential provider	161	1:23
•	Meeting with school	2	1:15
•	Meeting with therapist	23	0:46
•	Phone call with consultant	268	34:19
•	Phone call with day provider	87	0:24
•	Phone call with emergency services	49	0:34
•	Phone call with family	313	0:28
•	Phone call with physician	3	0:25
•	Phone call with psychiatrist	12	0:19
•	Phone call with residential provider	215	0:23
•	Phone call with school	5	0:17
•	Phone call with therapist	41	0:26
Outreach (OSTSL)	, Specialized Training, and Systems Linkages		
•	Clinical supervision calls or meetings	4	1:00
•	Planned contact with consultant	14	1:26
•	Planned contact with day provider	23	1:12
•	Planned contact with emergency services	0	0
•	Planned contact with family	36	1:12

		T .	
Planned	contact with physician	1	0:15
• Planned	contact with psychiatrist	7	1:26
• Planned	contact with residential provider	44	1:18
• Planned	contact with school	0	0
• Planned	contact with therapist	2	0:52
Provided	I training to day provider	0	0
<ul> <li>Provided</li> </ul>	l training to family	0	0
Provided	l training to residential provider	0	0
<ul> <li>Provided</li> </ul>	l training to school	0	0
Therapeutic Respi	te (TR)		
Facilitati	ng a planned respite admission	27	1:54
Facilitati	ng a planned respite visit	7	1:33
Facilitati	ing an emergency admission	15	2:28
Facilitati	ing in-home respite	32	2:10
Admissi	on/discharge review	10	1:51
<ul> <li>Discharge</li> </ul>	ge report writing	0	0
Weekly	team meetings	17	1:04
Emerger	ncy medical needs	2	3:30
Training	on findings and strategies	2	1:00
• Follow-ı	up/contact with teams, etc.	23	0:55
Travel ti	me related to Therapeutic Respite	44	1:49
• Visiting staff	a respite home to see client or work with	16	1:13